

DEVELOPMENTAL DISABILITIES WAITING LIST REPORT

FOR THE PERIOD OF JULY 1, 2008 THROUGH JUNE 30, 2009
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FOR:

The DEPARTMENT OF HEALTH AND SOCIAL SERVICES

AND

THE 26TH ALASKA LEGISLATURE

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ABOUT THE DEVELOPMENTAL DISABILITIES WAITING LIST REPORT

Under AS 47.80.130 (d), the Department of Health and Social Services is required to maintain a Waiting List noting individuals who experience a developmental disability as defined under AS 47.80.100 - 47.80.170. It is further required that an annual Report to the Governor and specified legislative committees be presented when there is not adequate funding to meet the needs of these individuals.

As noted elsewhere in this report, Alaskans who experience developmental disabilities may receive a variety of services administered and funded by multiple federal, state and local agencies. A centralized database has been developed to more easily determine what services, if any, a person on the Waiting List is receiving, how services relate to the client's needs as expressed in the client's assessment form, or whether the services requested are needed immediately or may be needed sometime in the future. Therefore, cost projections contained in this report should be considered estimates to use in planning and not a computation of the costs of comprehensive services that may be necessary to meet the needs of each person on the list.

The Division of Senior and Disabilities Services (SDS) and stakeholders from the advocacy community continue to work together to redevelop the policies and procedures that govern the management of the Waiting List. One of the recommendations made and adopted by the Ad Hoc Committee was to rename the DD Waitlist as the DD Registry to more appropriately reflect its intent and use. An additional recommendation made, adopted, and implemented over FY07 was a new tool to assess needs called the Developmental Disabilities Registration and Review. SDS continues to remove at least 200 individuals annually from the DD Registry via quarterly selections. The information individuals provide on the Developmental Disabilities Registration and Review tool is used to select those with immediate and significant need.

As part of a focused review of Home and Community Based Medicaid Waivers and Personal Care Assistance services, Centers for Medicare and Medicaid Services (CMS) directed the Department of Health and Social Services to temporarily stop accepting new enrollments to those programs effective June 26, 2009. That moratorium was lifted by CMS on August 28, 2009. During that time, individuals were still able to be placed on the DD Registry, and were still able to access DD Community Grant services. However, the moratorium did prevent SDS from conducting the July selection of 50 individuals from the DD Registry for fourth quarter FY09. Those individuals were noted in July 2009 per the normal process up to the point of removal from the DD Registry and notification. The selection process then proceeded as normal as soon as the moratorium was lifted. The data in this report include those individuals who, but for the moratorium, would have been removed from the DD Registry in July.

In addition to addressing issues related to individuals on the DD Registry, the Department of Health and Social Services has also partnered with Alaska Mental Health Trust Authority (AMHTA) and the Western Interstate Commission for Higher Education (WICHE) to assess the needs of, and available continuum of care for, persons who are now being placed out-of-state or are at risk of out-of-state placement due to complex behavior management. An issue analysis and options brief, published July 2009, presents the challenges and opportunities in Alaska's need to develop and sustain the capacity to serve individuals in our state. The brief is available at [http://www.hss.state.ak.us/dsds/pdfs/Issue Analysis and Options Brief - Final 7-31.pdf](http://www.hss.state.ak.us/dsds/pdfs/Issue_Analysis_and_Options_Brief_-_Final_7-31.pdf).

In conjunction with the Governor's Council on Disabilities and Special Education, AMHTA, and representatives of the Alaska Association on Developmental Disabilities (AADD), and with the support of DHSS and CMS, SDS remains committed to improving access to needed services and eliminating the need for a DD Registry.

SECTION 1:

THE PURPOSE OF THE DEVELOPMENTAL DISABILITIES (DD) WAITING LIST (AS 47.80.130(d) (1))

The DD Waiting List, henceforth in this report referred to as the DD Registry, presents information regarding people who have been determined eligible for developmental disability services and is used to select people for enrollment in services when resources are available. Additionally, the DD Registry assists SDS in planning for the future needs of people having a developmental disability. At least annually, SDS contacts those on the DD Registry to update personal information about changes in their condition or family circumstances.

Eligibility to be placed on the DD Registry or to participate in the Community Developmental Disabilities Grant (CDDG) program requires an individual to have a developmental disability as defined under the provisions of AS 47.80.900 (7). The term “developmental disability” means an individual with a severe, chronic disability that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the individual attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity:
 - Self care;
 - Receptive and expressive language;
 - Learning;
 - Mobility;
 - Self-direction;
 - Capacity for independent living;
 - Economic self-sufficiency, and;
- Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic assistance, supports, or other services that are of lifelong or extended duration and are individually planned and coordinated.

SECTION 2:

PLACEMENT ON THE LIST AND THE CRITERIA FOR RANKING AND SELECTION (AS 47.80.130(d) (2))

In order for a person to be eligible for the DD Registry, the individual must complete an Eligibility Determination application. This application provides the information needed for an SDS Health Program Manager to determine DD eligibility. Once individuals are determined to have a developmental disability, they are notified in writing and given instructions regarding how to complete the Developmental Disabilities Registration and Review form if they choose to be placed on the DD Registry.

The Developmental Disabilities Registration and Review (DDRR) form collects information about an individual's community participation concerns, living situation concerns, caregiver concerns, and need for services, including the projected timeframe for the need of a particular service. The questions attempt to measure immediate need and circumstances that might make a person vulnerable to crisis. A provider/grantee agency, Care Coordinator, SDS staff, or any applicant representative can assist a person or their family member with completing this form using an online submission form, emailing completed forms, or submitting completed paper copies. Once a DDRR form is received and the individual is placed on the DD Registry, the applicant or their legal representative is notified in writing with information about the DD Registry and the applicant's placement status. If an individual's life situation changes significantly, a revised DDRR may be submitted at any time. The DD Registry is maintained using the SDS data management system referred to as DS3.

Scoring Criteria used for Managing the Waiting List

A person's DD Registry score is figured electronically using the DS3 system. Each question was assigned a weighted set of possible scores by the Waiting List Ad Hoc Committee, which developed the tool. Each person's standing or rank on the registry is relative to the scores of all others on the list. Consequently, a person's rank can change depending on the relative needs of others on the registry. The tool uses a numerical assessment of need; the higher the need, the greater the number of points given. Individuals receive a written explanation of the scoring system along with a copy of their submission each time a new DDRR is received and scored by SDS.

Selection Methodology for Removing Persons on the Waiting List

Selection from the DD Registry is completed quarterly with the selection of at least 50 individuals with the highest need as evidenced by the highest numerical scores at the time of the selection. Individuals who have been selected from the DD Registry are

notified via certified mail of their selection, including information about the “next steps”. SDS Grants Unit works with DD Community Grantee Agencies to reallocate grant funds freed up by individuals selected from the DD Registry for MRDD Waiver services.

SECTION 3:

BASIC DEMOGRAPHIC INFORMATION (AS 47.80.130(d) (3) & (AS 47.80.130(d) (6))

The following demographic information represents the status of the Registry population during the State of Alaska fiscal year beginning July 1, 2008 through June 30, 2009. Since the registry is constantly evolving, this data represents the specified period and may not reflect the current state of the registry. The historical demand for services reflects minimal variance in population, geographic distribution, and services requests over time. The following data was taken from the DS3 data management system, which is used by SDS to maintain the DD Registry.

Overview of Individuals on the Waiting List

| | |
|--|------------------|
| Number of individuals on the list as of 6/30/2009: | 972 |
| Number of individuals 22 years old or younger as of 6/30/2009: | 700 |
| Number of individuals on the list for 90 days or more | 897 |
| Average length of time for individuals on the Registry | 50 months |

Age of Individuals on the Waiting List

| Age Range | Number of Individuals | Percentage |
|-----------------------|------------------------------|-------------------|
| 0 to 3 years of age | 53 | 5.5 |
| 4 to 17 years of age | 471 | 48.5 |
| 18 to 21 years of age | 147 | 15.1 |
| 22 to 64 years of age | 300 | 30.9 |
| Over 65 years of age | 1 | <1 |
| Total | 972 | 100% |

Gender of Individuals on the Waiting List

| Gender | Number of Individuals | Percentage |
|---------------|------------------------------|-------------------|
| Male* | 602 | 61.9 |
| Female | 370 | 38.1 |
| Total | 972 | 100% |

* This statistic is consistent with statistics on the national prevalence rate of developmental disabilities among males and females.

Race & Ethnicity of Individuals on the Waiting List

| Ethnicity | Number of Individuals | Percentage |
|------------------|------------------------------|-------------------|
| Alaska Native | 223 | 22.9 |
| Asian | 45 | 4.6 |
| Black | 28 | 2.9 |
| Hispanic | 16 | 1.7 |
| Pacific Islander | 9 | <1 |
| White | 576 | 59.3 |
| Other | 75 | 7.7 |
| Total | 972 | 100% |

Geographic Distribution of Individuals on the Waiting List by Regional Service Area

| DD Service Region | Number of Individuals | Percentage |
|--------------------------|------------------------------|-------------------|
| Anchorage | 450 | 46.3 |
| Interior | 154 | 15.8 |
| Northwest | 45 | 4.6 |
| Southcentral | 197 | 20.3 |
| Southeast | 76 | 7.8 |
| Southwest | 50 | 5.1 |
| Total | 972 | 100% |

Services Received by Individuals on the DD Waiting List

Analysis of program data indicates that in FY 2009, 594 individuals (61.1%) on the DD Registry received some services through the DD grants program administered by SDS.

Individuals currently served out-of-state in an Intermediate Care Facility for the Mentally Retarded (ICF/MR) are not maintained on the DD Registry. However, the 8 individuals out-of-state in FY 2009 represent a lack of resources available to meet their needs within Alaska, and therefore are pertinent to the spirit of this report on the unmet needs of individuals experiencing developmental disabilities. In FY 2009, an additional 10 individuals had been referred to an ICF/MR out-of-state and were in either the preliminary referral process or waiting for availability of a placement.

SECTION 4:

NEEDS, PREFERENCES, AND ESTIMATED COST TO SERVE INDIVIDUALS ON THE WAITING LIST (AS 47.80.130(d) (4))

One of the functions of the Developmental Disabilities Registration and Review is to gather information on the services individuals feel they need. This data allows the state to project the cost of serving these individuals. Most people on the registry request more than one service, although there are some who have not requested specific services.

Projected Annual Cost

The following annual cost projection represents SDS' best estimate to serve all of the individuals on the registry who indicated a service need(s), with the assumption that they would be served in the Medicaid Waiver program. It is well documented that not all individuals on the registry are eligible for waiver services or accept the services when offered them. Approximately thirty percent of individuals selected in the quarterly selections do not result in participation in waiver services because they do not qualify for the Medicaid Waiver, decline the program, or are otherwise unavailable to participate. However, the Medicaid Waiver program reimbursement rates provide the most accurate cost data upon which to base budget projections.

In accordance with state law, SDS attempts to tailor services to meet individual needs. The average annual costs listed in the following table represent an average of the rates for service in FY 2009. The rates in the table shown below do reflect a 1.5% increase for Home and Community-Based Services extended for FY09. Not accounted for in the cost estimates below are costs associated with provider capacity building and infrastructure to support the provision of requested services. Under the American Reinvestment and Recovery Act of 2009, the federal share (FMAP) for Medicaid services was increased temporarily. This increase is anticipated to sunset at the end of calendar year 2010 without additional Congressional intervention. Therefore, state costs for services are anticipated to increase annually from the total reflected below.

There are some service characteristics pertaining to rates that are worth noting:

1. The Care Coordination service rate is calculated assuming that an individual receives this service for an entire year.
2. Intensive Active Treatment (IAT) rates are variable depending upon the service, provider, and community in which the service is obtained. The IAT average is a good-faith estimate of the cost for this service.

3. Respite and Chore service estimates have been calculated at the maximum allowed cost, and therefore represent a liberal estimate of the cost to provide these services.

4. The Environmental Modifications cost represents the maximum allowable cost over three years of service, with the presumption that the entire cost would be granted during the first year of service.

| Type of Service Requested | Average Annual Cost | Number of Requests | Projected Cost |
|---|----------------------------|---------------------------|-----------------------|
| Family Habilitation | \$43,437.94 | 91 | \$ 3,952,853 |
| Group Home | \$100,915.12 | 59 | \$5,953,992 |
| In-Home Support | \$25,480.07 | 414 | \$10,548,750 |
| Shared Care | \$16,091.83 | 50 | \$ 804,592 |
| Supported Living | \$49,539.31 | 154 | \$7,629,053 |
| Total Cost for Residential Rehabilitation Services | | | \$ 28,889,240 |
| Respite | \$7,005.63 | 634 | \$ 4,473,270 |
| Supported Employment | \$12,258.68 | 266 | \$ 3,260,810 |
| Day Habilitation | \$17,121.83 | 511 | \$ 8,749,256 |
| Care Coordination | \$2,992.63 | 671 | \$ 2,008,052 |
| Intensive Active Treatment | \$5526.07 | 218 | \$ 1,204,682 |
| Transportation | \$1,772.35 | 342 | \$ 606,145 |
| Environmental Modification | \$10,000 | 174 | \$ 1,740,000 |
| Chore Services | \$1,795.58 | 80 | \$ 143,646 |
| Total Cost | | | \$ 51,075,101 |
| Total State Cost with FMAP at 61.12% | | | \$ 19,857,999 |

SECTION 5:

**NUMBER OF INDIVIDUALS SELECTED OR REMOVED FROM THE WAITING
LIST, FY09
(AS 47.80.130(d) (5))**

| Reason for Removal | Number of Individuals |
|---------------------------------|------------------------------|
| Needs met by another DD program | 23 |
| Selected for waiver services | 253 |
| Not eligible for DD services | 45 |
| Total | 321 |

SECTION 6:

NUMBER OF STUDENTS WITH DEVELOPMENTAL DISABILITIES IN SPECIAL EDUCATION

(AS 47.80.130 (d) (7))

It is important to note that Special Education and the services provided through SDS programs are different. Special Education provides specially designed instruction in the school setting. Local education authorities under the purview of the Alaska State Department of Education and Early Development (DEED) administer these programs. SDS programs provide for services and supports in the home or community to assist the individual and their family to participate in community life and avoid institutional placement. Another key distinction between special education and the SDS programs is that, for those who qualify, Special Education is an entitlement; SDS programs discussed in this report operate within the limits of annual legislative appropriations and the capacity of the state and community to provide the desired services.

According to the Department of Education and Early Development (DEED), there are about 17,662 students age 3 to 22 in Special Education (FY 2009 Child Count). Among these Special Education students, approximately 4053 may have developmental disabilities. Individuals with the following types of developmental disabilities may be receiving special education services across the state: mental retardation, cerebral palsy, autism, and seizure disorder. Similarly, children with a severe emotional disorder or Fetal Alcohol Syndrome may qualify as having a developmental disability if they experience substantial limitations in functional abilities.

SECTION 7:

COPIES OF REPORTS, POLICIES, MANUALS, AND PROCEDURES (AS 47.80.130 (d) (8))

Copies of this report and the forms used to manage the Registry are available on the website of the Division of Senior and Disabilities Services at:

<http://www.hss.state.ak.us/dsds/dd/>

Copies of this report, policies, and forms used to manage the Registry may also be obtained by requesting them from the Division of Senior and Disabilities Services at the following address or phone number:

**The Division of Senior and Disabilities Services
550 W 8th Avenue
Anchorage, Alaska 99501
(907) 269-3666
or
Toll Free at 1-800-478-9996**